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ABSTRACT

This final report describes accomplishments and activities of a four-year federally funded Rhode Island project for children who are deaf blind. Major accomplishments included: (1) parents (of 65 identified individuals) received greater access to an increased number and variety of support resources; (2) professionals linked to individuals with deaf blindness increased their competencies through technical assistance and consultation services provided to over 25 school districts and via more than 20 graduate and undergraduate courses; (3) children with deaf-blindness increased their access to general education (doubling from 10 percent to 20 percent) and demonstrated growth through alternative assessment measures; and (4) the Rhode Island system of services became better able to meet the needs of children with deaf-blindness and their families as demonstrated in such areas as increased capacity to provide functional assessments of hearing and vision. Individual sections address each of the project's seven goals, problems encountered and how they were solved, and implications for policy, practice, and research. (DB)

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Rhode Island Project for Children who are Deaf-Blind

Final Report

1995 – 1999

Submitted by

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Executive Summary

Throughout 1995 - 1999, Rhode Island Project for Children who are Deaf-blind (RIDB) was managed by the University Affiliated Program of Rhode Island (UAP) at Rhode Island College with the cooperation and support of the Rhode Island Department of Education, Office of Special Education. The UAP has been in existence since 1993 and offers a variety of interdisciplinary and family focused training, outreach, technical assistance and dissemination activities. Rhode Island College, the site of the UAP, houses the only preservice training programs in Rhode Island that focus on the preparation of personnel for careers in Early Intervention, and for careers with students who have severe or multiple disabilities including sensory impairments.

In general terms, the major benefits of this grant were defined for parents, professionals, children with deaf-blindness, and the systems which support these children.

- **Parents received greater access to an increased number and variety of support resources** through home visits, UAP and *Sensory Connection* newsletters, and linkage with other state and national supports. RIDB continued its support to families of the 65 individuals with deaf-blindness on the current Rhode Island grant census. Home visits, phone consultation, support at IFSP, IEP, and transitional meetings were activities used to achieve these benefits.
- **Professionals linked to individuals with deaf-blindness increased their competencies needed to meet the needs of these children.** The RIDB became a valued participant in the complete Early Intervention system through the Rhode Island Department of Health, provided technical assistance and consultation to over 25 school districts within Rhode Island, and provided transition support and training to the majority of agencies who

provide services to adult-aged individuals with deaf-blindness. Professionals were linked with "mentor" teachers to provide direct support.

At the inservice and university level, content related to deaf-blindness was incorporated into coursework in more than 20 graduate and undergraduate courses. Based on current research, this content entered courses in the fields of Special Education, General Education, Physical Education, Occupational Therapy, Physical Therapy, and Social Work.

- **Children with deaf-blindness increased their access to general education, and demonstrated growth through appropriate assessment means.** Children with deaf-blindness who receive their education in public schools rose from 10% in 1994 to 20% at the end of this grant's four year period. Consistent with the reauthorization of IDEA, all children who receive special education must tie current IEP goals to the general education curriculum. RIDB provided inservice and college coursework attended by over 75 professionals on this topic.

  Documenting the growth of children with deaf-blindness was a second challenge of RIDB. Grant staff participated in the Rhode Island Alternative Assessment Workgroup. Perspectives which include dual sensory loss were discussed and incorporated into test sites proposed for the 1999-2000 initial Alternative Assessment phase. Grant staff will continue this training as Alternative Assessment expands to all Rhode Island classrooms with children who qualify.

- **The Rhode Island system of services is better able to meet the needs of children with deaf-blindness and their families.** One target area of system development was to increase state capacity to provide functional assessments of hearing and vision. During the four year grant period, two VIISA (Vision In-Service In America developed by Utah

State University) courses resulted in the training of 25 individuals able to perform a basic assessment of vision. Thirty five additional professionals were trained by project staff to perform more in-depth vision and hearing assessment of children with both vision and hearing loss.

Describe the Project

Rhode Island Project for Children who are Deaf-blind employed a core staff of two individuals: Susan J. Dell, Ph.D., and Margaret McNerney, M. Ed., who share the responsibility of providing services to project participants. Ms. McNerney, at .5 FTE, provided technical assistance and consultation to both school professionals and parents. Dr. Dell, at 1.0 FTE, also provided these services, but provided the majority of inservice training, university courses, administrative responsibilities, product and newsletter development. Additional services were provided by the Pat Belcher (.1 FTE), the UAP Coordinator of Children's Services, Dr. John Susa (.15 FTE), the UAP Assistant Director for Family Support, and Erika Tuttle (.2 FTE), UAP Clerical Support. The project was written to encompass seven basic goals. As stated, these goals are:

1. To provide information and support that will assist in empowering families of children with deaf-blindness to assist their children in becoming active participants in home, school and community.
2. To provide technical assistance to professionals working with children with deaf-blindness, birth through two years of age.
3. To provide technical assistance to professionals working with children with deaf-blindness, ages three through twenty-two.

4. To create a network of experienced mentors at all age groups who will provide technical assistance to other service providers.
5. To increase the availability of information, technical resources, preservice training, and inservice training for both parents and professionals.
6. To develop in Rhode Island and increased number of professionals with competence in conducting functional evaluations of vision and hearing . To make this resource available to increased number of children
7. To facilitate systems change in the manner in which pre-school and school services are delivered to children with deaf-blindness in Rhode Island.

Context

Previous applications for the Rhode Island Project for Children who are Deaf-Blind (RIDB) have been submitted by Meeting Street Center, a segregated educational facility that provides educational and related services to children with multiple disabilities. Movement to the University Affiliated Program of RI (UAP) offered a three essential benefits: increased network of school support resources; increased intensity of family supports; and an affiliation with a agency which supports the inclusion of all individuals in school, work, and society. To this end, the UAP has either become responsible for or developed collaborative relationships with several school and family support resources. These include: (a) the Schools Project of Rhode Island Tech ACCESS Center which provides evaluation and technical assistance regarding assistive and/or adaptive technology; (b) the Traumatic Brain Injury Resource Center which provides information and assistance to both families and schools; (c) a network of mentor teachers who

are available to assist teachers to design and implement inclusive school practises; (d) a Positive Behavioral Supports training and technical assistance network, and others.

Describe How the Goals were Accomplished

Goal 1: To provide information and support that will assist in empowering families of children with deaf-blindness to assist their children in becoming active participants in home, school and community.

This goal was accomplished primarily through direct contact with project families. Families with children under 3 years of age received home visits on a bimonthly basis with telephone and mail contact made during alternating months. Families with children of school age received visits two times per year, or more frequently if the family requested. The focus of home visits was determined by the family. Visits often dealt with issues such as child care strategies, IFSP and IEP involvement, communication strategies which highlight a child's strengths, assistive devices, orientation and mobility, family recreation, access to services in the school or the community, or any other area of need which the family identifies. Families were provided an expanded access to information and resources at the local, state and national levels. As part of the UAP network, information was disseminated from all appropriate UAP resources, beyond the information provided by the project. The project related newsletter, entitled *the Sensory Connection*, provided families and professionals with information on "best practices" in the field, updates on new technology which might support home activities, and highlights of local and national conferences and family resources. *The Sensory Connection* was published on a biannual basis.

Goal 2: To provid technical assistance to professionals working with children with deaf-blindness, birth through two years of age.

The key factor in achieving this goal was to increase the visibility of the RIDB project to professionals in the Early Intervention (EI) System. Project staff made visits to each EI center (5 centers in Rhode Island), provided an overview of the project and reviewed the referral process. In addition, project staff scheduled meetings with staff at Women & Infants Hospital, the only level 5 neonatal unit in the area. Many children with health issues receive their initial care at this facility. As a result of these visits, there has been an increase in the children referred for RIDB services from three of the five EI regions. Project staff provided over 70 instances of technical assistance to children in the birth to 3 year period over the course of this grant. As described in Goal #1, home visits to children involved with the project were made jointly with Early Intervention professions to increase the level and frequency of support to children and families. In addition to home visits, project staff attended transition meetings for children transitioning to preschool services. *Project VIISA*, an inservice education course which focuses on the needs of infants and toddlers with vision impairments and other disabilities occurred during the four year grant period. Project staff worked collaboratively with agencies in Rhode Island and Massachusetts to plan, fund, implement, and teach this course. Collaborating agencies included RI Department of Health Early Intervention, RI Department of Education Vision Teachers, Perkins School for the Blind, and the UAP of Rhode Island. As a result, 10 professionals from Rhode Island gained the skills to successfully complete this course

Goal 3: To provide technical assistance to professionals working with children with deaf-blindness, ages three through twenty-two.

The goal for all children and youth with deaf-blindness is to maximize their meaningful inclusion into their home, school, and community. One focus of this involvement is contact with individuals without disabilities. With this in mind, project staff provided 120 opportunities for technical assistance to professionals of school-aged children over this grant period. The focus of technical assistance varied, based on the individual needs of each child. Educational intervention and programming (frequently related to the inclusion of children into the general education curriculum), information, recreation & leisure, and issues related to assistive technology comprised the topics most requested.

Individuals with Disabilities Education Act (IDEA) mandates the assessment of all children who receive education. For many individuals with deaf-blindness, **Alternate Assessment** is the best means to meet this mandate. Project staff participated on Rhode Island Alternate Assessment planning teams, and will be involved in the implementation process to all students in Rhode Island who qualify for this assessment.

Many individuals with deaf-blindness in Rhode Island and throughout the country also experience additional disabilities including complex health needs. As a result, many students involved with the project pass away prior to a transition to adult services. Over the past grant cycle, two students participated in **transition to adult services**. RIDB project staff were actively involved in all meetings related to these transitions and provided technical assistance and support to make this transition smooth and adult services meaningful for these students. A variety of RI adult service agencies, RIDB, UAP, and the National Technical Assistance Consortium (NTAC)

worked together throughout the four year period to provide state-wide education with the focus of improving the skills of paraprofessionals and professionals in issues related to sensory impairment. Two state-wide conferences, and one topic inservice assisted over 120 participants increase their competencies. As a result, one student with deaf-blindness has transitioned to adult services and is enrolled in meaningful employment, and resides in an adult residential home with ongoing family involvement in his life.

Goal 4: To create a network of experienced mentors at all age groups who will provide technical assistance to other service providers.

The UAP of Rhode Island has a current network of experienced mentors who are available to provide technical assistance to other professionals. Throughout the four year grant cycle, four teachers accessed the system of UAP mentor teachers for support and technical assistance related to the inclusion of students with sensory and multiple disabilities. Teacher to teacher contact provided a valuable support to these teachers. Team management,. Paraprofessional support, involving professionals in general education, alternate assessment, and assistive technology were additional areas of support.

Goal 5: To increase the availability of information, technical resources, preservice training, and inservice training for both parents and professionals.

Rhode Island College is the sole source in Rhode Island for related preservice training. The UAP is intimately linked with the early intervention preservice program and is responsible for implementing the severe/multiple disabilities program.. Over the past four years, project and UAP staff incorporated content relating to individuals with deaf-blindness into over 20 graduate

and undergraduate courses offered at four colleges (Providence College, Rhode Island College, University of Rhode Island, and Community College of Rhode Island). During the Spring semester, project staff taught Special Education 526: a course that focuses on students with multiple and sensory disabilities. Best practices on research supported curriculum, methodology, and assessment is the content of this course.

The UAP of Rhode Island implements a Personnel Preparation grant which enabled over 40 preservice students in fields of study including Occupational Therapy, Special Education, Speech and Language Pathology, Physical Therapy, and Educational Psychology. Personnel Preparation grant participants were enrolled in programs from CCRI, Rhode Island College (3 departments), and University of Rhode Island. Experiences provided by this grant included time with families of children with deaf-blindness, in addition to classroom involvement of older individuals in school settings. Students were exposed to many issues facing families and educators related to children with sensory disabilities.

The Sensory Connection newsletter was developed and disseminated to 200 families, professionals, and paraprofessionals involved with the project. As described in Goal 1, the focus of this newsletter was increasing the knowledge of the readers in terms of research, inservices, resources, and ideas to support the involvement of individuals into school, family, and the community. Project participants received access to all pertinent resources, newsletters, inservice notices, conference information, and linkages to other UAP programs and supports.

Internet access has been a goal of RIDB throughout the past four years. All project staff now have e-mail accounts and use this means to provide information to parents and professionals. Project staff have been involved in the development of a UAP website which includes information related to RIDB activities.. The goal of the web site is to provide

information on individual UAP projects, trainings, resources, and UAP developed products which are available for purchase.

As part of the UAP team, issues relating to sensory disabilities were included into Part B CSPD and the Part H CSPD as well as the interagency CSPD that collaboratively design interagency trainings. RIDB project staff were involved in the planning and implementation of the Early Intervention program entitles "Faculty and Friends of Early Intervention," a forum for individuals linked to EI to increase their knowledge and competencies related to young children with disabilities.

Goal 6: To develop in Rhode Island and increased number of professionals with competence in conducting functional evaluations of vision and hearing . To make this resource available to increased number of children.

Project VIISA, a program developed through SKI-HI Institute at Utah State University was offered during this grant period. This intensive on-site/distance learning approach used to develop skills and competencies related to evaluating vision in a functional way, and using this information to plan and implement effective educational programs occurred during Project year Three (Infant-Toddler version) and Four (Preschool version). Twenty participants from Rhode Island successfully completed these courses.

Curriculum related to providing and utilizing Functional Vision Evaluations was newly incorporated into SPED526, a graduate course taken by 35 students throughout the four year grant period. These students were required to demonstrate their competencies in using these techniques throughout the course. Similarly, curriculum related to Functional Hearing Evaluation was also incorporated into SPED526.

Professionals involved with RIDB students were given technical assistance on completing and utilizing functional vision and hearing evaluations by project staff. Ten students utilized this assistance throughout the four year period and expanded their analysis of vision and hearing to other students.

Goal 7: To facilitate systems change in the manner in which pre-school and school services are delivered to children with deaf-blindness in Rhode Island.

At the level of early intervention, three children with deaf-blindness received support by day care providers in inclusive pre-school/daycare settings. This was the first opportunity for RIDB staff to provide support to children at this age in out-of-home experiences. Project staff provided technical assistance on assistive technology to support learning, implementing natural routines, establishing initial communication systems, and general information on children with developmental disabilities. Technical assistance involved the child, his/her family, daycare providers, early intervention professionals, and other support personnel. Three of these children continued this experience until their transition into formalized preschool special education programs at age three.

As professionals in Rhode Island receive information through college courses, RIDB project activities, UAP networks, and beyond, children with deaf-blindness receive improved services in environments which facilitate meaningful contact with individuals without identified disabilities. Teachers are better prepared to participate in alternative assessment and are able to document the growth of each child's program and individual skills. During the four year grant period, parents, teachers, and others who support individuals with deaf-blindness received

almost 200 opportunities for technical assistance and benefited from 12 publications related to deaf-blindness.

Problems encountered and how they were solved

As grant years progressed, it became apparent that efforts to organize and facilitate a "Family Weekend" were unsuccessful. Rhode Island families involved in the RIDB project were often overwhelmed with the medical and schedule needs of their children and found committing to full weekend plans difficult. One solution to this problem was to link up with other states to facilitate day involvement with other families rather than full weekends. RIDB staff united with the Perkins School for the Blind Preschool Program to plan, assist with funding, and facilitate an annual day conference. This conference was attended by 10 Rhode Island families with young children with vision impairments and deaf-blindness each year. To assist with travel difficulties, RIDB arranged, in coordination with the Lions Foundation, a bus to transport any interested families to the May conference.

During grant years three and four, several families (4) were identified to RIDB as having children identified with Usher Syndrome. Linkages with regional efforts to meet the needs of these families were made. During grant year four, these families were invited to regional family weekends (New Jersey, New York, Connecticut), although no families from Rhode Island chose to attend. These efforts will be continued in future years.

The *Sensory Connection* newsletter was found to take considerable time to develop, review, and disseminate. Many articles included in the *Sensory Connection* were created by families and Rhode Island professionals. The dissemination schedule was changed from quarterly, to

two times per year. The original dissemination number jumped from 80 individuals and topped at 200 individuals by grant year four.

Implications for Policy, Practice, and Research

Over the past four years, RI Services for Children with Deaf-blindness (RIDB) grant activities have led to changes in policy, practice, and future research in issues pertinent to individuals with deaf-blindness. The improved relationship between Rhode Island State Department of Education Vision Teachers (RIVT) resulted in many joint ventures. RIDB and RIVT established joint inservice education efforts (Project VIISA preschool and infant courses) which increased the local capacity of families and professionals involved with young children with vision loss.

RI Usher Syndrome Task Force, a new group with the charge of improving the services and assistance to children with Usher Syndrome, their families, and professionals. Representatives from RIDB, RI Vision Teachers, and RI School for the Deaf attended numerous workshops and inservices together to meet this group's charge. A process to identify children with Usher Syndrome through a formalized screening at RI School for the Deaf is currently planned.

One of the primary goals of RIDB is to support children with deaf-blindness in inclusive settings. At the onset of this project (1994) only 4 children of school age on the project census (10%) received education connected with a regular classroom. These statistics were far below that of the national average of 47% of students with deaf-blindness who receive education at a public school. As of 1999, the percentage of children who receive education in public school settings is 20%, or 12 children. Although much work remains, this increase in the capability

and willingness of public school personnel to meet the needs of children with deaf-blindness is significant.

The involvement of RIDB in the Alternative Assessment work groups ensured that the specific needs and abilities of individuals with deaf-blindness would be captured in the new Alternative Assessment process. Examples of how to include children with significant sensory loss continues to be a challenge, and RIDB's input into this practice will enable this group to be represented and supported as Alternative Assessment test sites and in state-wide implementation. RIDB and the UAP of Rhode Island will also be key members of the Alternative Assessment Training Team planned for the 1999-2000 School Year.

Providing parental support was the highest priority throughout the past four grant years. The UAP Parent Consultant and parent of three children with special needs, Dr. John Susa, assisted in numerous situations regarding the needs of parents, accessing the web of services at the local, state, and national level, and provided representation in may parent focused groups. Dr. Susa's role in RIDB will increase in future grants. The level of contact with parents (2 visits a year to families of school aged children and bi -monthly visits for families in early intervention) continued throughout the four grant years, but the access to an expanded array of information and services grew. As part of the UAP network of services, families were informed of UAP activities and supports beyond those directly offered by RIDB.